Neutral Citation Number: [2022] EWCOP 53

Case No: 13905631

IN THE HIGH COURT OF JUSTICE
COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 16/12/2022

Before:

THE HONORABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

- -

Between:

TN

Appellant

- and –

(1) An NHS ICB

(2) RN
(by his Accredited Legal Representative, Jolanta Edwards)

Respondents

- -
- -

(**Mr Paul Diamond** instructed by **Stephen Jackson at Jackson Osborne**) for the **Appellant**
(**Mr Adam Fullwood** instructed by the **Rachel Kelly-Brandreth at Hill Dickinson**) for the **First Respondent**
(**Mr Oliver Lewis** instructed by **Paul Williams at Peter Edwards Law**) for the **Second Respondent**

Hearing dates: 8th December 2022

- -

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....

THE HONOURABLE MR JUSTICE HAYDEN

MR JUSTICE HAYDEN:

1. This is an application, on behalf of TN, who seeks permission to appeal the judgment and consequential orders of HHJ Burrows, dated 28th September 2022. The Judge had been considering two questions, relating to a Covid-19 vaccination, in respect of TN's 22-year-old son:

    i. Does RN (the son) lack capacity to take the decision himself?
    ii. If so, whether it is in RN's best interests to receive the vaccine in accordance with the plan set out by his General Practitioner?

2. The question of RN's capacity was not contentious. All agreed that he does not have the capacity to take the decision for himself. HHJ Burrows concluded that it was in RN's best interest for him to be vaccinated. The Judge plainly gave the case great care, he reserved judgment and received detailed written and oral argument.

3. RN suffers from severe learning disability, a Partial Trisomy 13 (three copies of one chromosome), a Tetralogy of Fallot (a combination of four congenital heart defects), last repaired in 2001. The latter is particularly troubling to TN. She has developed a real anxiety that the vaccine is more likely to cause her son serious harm because of his heart condition. The Partial Trisomy 13 has had a significant effect on RN's cognitive behaviour.

4. RN lives with his mother, who is his carer. Throughout the 'lockdown' periods, she has been his sole carer. RN's parents are separated. RN does not have contact with his father. The Judge did not hear evidence from RN's father, nor did he contribute directly to the hearing. The Judge noted that *"It was mentioned in the Court papers that he [the father] was in favour of RN receiving the vaccine"*. However, the Judge regarded that as evidence upon which he felt unable to rely.

5. The issue of the vaccine was first raised, some time ago by Dr C (General Practitioner) with TN. In 2021 there were discussions with her as to whether some agreement could be reached in relation to vaccination. This was not possible. In order to address, and perhaps allay, TN's concerns, Dr A (a Consultant Cardiologist) was asked to give an opinion. In September 2021, he concluded that it was in RN's best interests to have the vaccine, for the reasons I will refer to below.

6. An application was made to the Court of Protection in March 2022. The progress of the case has been alarmingly slow. This appears partly to be due to the fact that the case was adjourned to await the outcome of an appeal in another case. Sadly, that appeal was not concluded, due to the death of P.

7. HHJ Burrows noted that Dr A had already been involved with RN before the vaccination issue was raised and therefore, had some familiarity with his medical situation. As the Judge noted, Dr A, in his first report dated the 2nd September 2022, focused in careful detail, on any vulnerability that might arise for RN in consequence of the heart conditions from which he suffers. HHJ Burrows set out the key parts of Dr A's report. I do the same, though slightly more extensively:

> *"11. Tetralogy of Fallot is a reasonably common (1:2500) congenital cardiac problem usually detected at birth (or antenatally by ultrasound),and repaired surgically in the first few years of life. Sometimes Tetralogy of Fallot is associated with genetic changes. In RN's case cardiac development occurred differently in the presence of the extra genetic material he carries (three copies of part of chromosome 13). This genetic change is also linked to other developmental matters, including cleft lip/palate and cognitive development. Normally children born with complete trisomy 13 (Patau's syndrome, frequency 1:16000) do not survive the first year of life. Partial trisomy 13 can be less severe, but patients surviving to adulthood are very rare. RN's prognosis will therefore be shaped by the natural history of partial Trisomy 13 in addition to the natural history of repaired Tetralogy of Fallot. In the first witness statement from TN it is acknowledged that RN has a life limiting condition (at paragraph 31) due to the chromosomal abnormality, with attendant learning difficulties that lead to a lack of capacity (paragraph 23), and unable to verbalise physical symptoms (paragraph 69). There are no treatments for chromosomal anomalies at present.*
>
> *12. With regard to the underlying cardiac diagnosis, the need for lifelong cardiac surveillance for repaired Tetralogy of Fallot relates to the need for re-operation to the pulmonary valve in ~40% of patients by the third decade of life, in addition to the later risks of rhythm abnormalities, which do come with an attendant risk of sudden death as set out in point 11 above. Although the global experience with tetralogy repair is now significant, because this is a surgery delivered in infancy from the 1970's we have very few patients in their sixth decade of life (or older) who may be able to inform of the longer-term cardiac prognosis. In my own clinical practice, I have not yet looked after a patient with repaired Tetralogy of Fallot into their eighth decade of life for example. However, it is now expected that patients born with Tetralogy of Fallot will now survive well into adulthood (discussed in point 18 below).*
>
> *13. In contrast the documented natural history of partial trisomy 13 in adulthood is scant. The world's largest case series (Am J Med Genet.2021;185A:1743–1756) for complete trisomy 13 has 11 individuals over 18 years old. I am unable to find an equivalent case series for partial Trisomy 13. In other words, it appears that chromosomal anomalies are likely to impact prognosis more than the cardiac aspects. Put simply, there are many adults with repaired Tetralogy of Fallot, and few with partial Trisomy 13"*

8. The Judge was entirely correct to highlight the following passages in Dr A's report, it has resonance for reasons which I will return to below:

> *"We are nearly two years from the point of vaccine roll out, and although some cardiac issues have been raised that are attributable to the vaccine, cardiac issues (typically this means myocarditis)* ***are worse following natural infection than cardiac issues associated with vaccination even with sequential (i.e., booster) dosing."*** (my emphasis)

9. It is also important to set out the following paragraph which the Judge also plainly had in mind:

> *"I am not aware of any specific reports that have identified patients with particular types of heart disease being more (or less) vulnerable to vaccine related complications. The most recent COVID vaccination guidelines from the UK's congenital cardiac disease society continues to advocate for vaccination, and for booster vaccination. Young males may be more at risk from particular vaccine regimes from a myocarditis perspective, but there are alternative explanations for those findings, and also alternative vaccine strategies that are not encumbered by such concerns*."

10. Thus, it requires to be stated and in clear terms, that the evidence before the Judge revealed no heightened risk to RN in receiving the vaccination. Moreover, the evidence, as highlighted in the judgment, identified from a statistical basis, a heightened risk to RN of not having the vaccine. This was expressed in Dr A's report as follows:

> *"I note early reports of six-fold increases in mortality following natural COVID infection in patient groups with learning disability and the potential for this group of patients to be at risk of health inequality when vaccine access is considered. Hospitalisation is also increased in this group."*

11. On the matrix of this medical evidence, it is clear that Judge Burrows could have reached no other conclusion in respect of RN's best interests medically. However, as the jurisprudence of the Court of Protection has made abundantly clear, a finding that P (the protected party) lacks capacity to take a decision for himself does not mean that his wishes and feelings are irrelevant. On the contrary, they remain part of the wider forensic landscape and are mandated for consideration by Section 4 of the Mental Capacity Act 2005. I was concerned that the voluble force and sincerity of TN's own views, which have been the focus of much attention by both the doctors and the parties, may have drowned out RN's voice, both generally and for the Judge. Though it was not raised as a point of appeal by Mr Diamond, who acts on behalf of TN, I was prepared to investigate whether this important aspect of the required evaluation had been undertaken with sufficient rigour.

12. Mr Fullwood, who appears on behalf of the NHS Integrated Care Board, also appeared in the Court below. He submitted that whilst the Judge had said *"I cannot establish what his wishes and feelings are, or what he has in the past wished for"*, he nonetheless, extended his enquiries to incorporate RN's likely response to the practicalities of having

the vaccination. I agree with Mr Fullwood that this is an important part of the broader forensic landscape. What also emerges is that the Judge had plainly read the attendance note of RN's Accredited Legal Representative and recognised its contribution to identifying the central importance of affording respect for RN's autonomy in the construction of the care plan.

13. For completeness, I set out key passages in the note which have been focused upon in the course of this appeal:

> *"LL asked TN whether RN could interact non-verbally if he wanted something. TN explained that RN is mobile so he can get up and get something himself or he will take your hand and pull you towards what he wants. TN said that RN's life is food, family and things he enjoys, like reading. LL asked TN if RN could read, TN said that he could not but he likes the pictures in books. TN showed LL a children's books with pictures of animals in it. TN explained that RN looks at the pictures and she then talks about the pictures, and stated RN is mad about cats and rabbits in particular."*

14. RN plainly derives enjoyment from life. Though he cannot communicate verbally, he is able to reveal his wishes and feelings (which are not synonymous) to those around him by his general behaviour and reactions. The attendance note provides an example of this:

> *"LL asked TN whether she felt RN was aware of the pandemic at all. TN said that the only change to RN's life was that people around him started wearing masks and this scared him, and he tried to take them off people. TN told a story of a lady wearing a visor which RN tried to take off her. TN reiterated that this was the only thing RN would see as different in life."*

15. The preponderant evidence before the Judge indicated that RN was not anxious about receiving injections or having blood taken. Insofar as TN has, through her Counsel at this appeal, insinuated anything to the contrary, I regard that as being opportunistic, and unsupported by the evidence. Neither was it the case she advanced to Judge Burrows. Additionally, the medical records reveal *"all the usual vaccinations for a man of RN's age"*, and until recently including the flu vaccine. He also has regularly required blood testing. Moreover, TN for what Mr Diamond volunteered were "forensic reasons", was taken by his mother for a blood (antibody) test to identify whether he had been infected by the Covid-19 virus. This was done on 29th March 2022. For completeness, I record that the test was positive, and it is therefore likely that RN has been infected with coronavirus (SARS-CoV-2) at some point in the past. In the light of paragraph 8 above, this should afford TN some reassurance.

16. The care plan which the Judge specifically endorsed, both in the judgment and in his order, recognised that RN would most likely comply with vaccination if suitably assured. The Judge made the following *'factual finding or evaluation'*, as he described it:

> *"So far as the administration of the vaccine is concerned, the care plan does not envisage the need for physical intervention (beyond the gentle holding still of the target arm), and no problems are anticipated."*

17. Though the Judge felt unable to *"establish what [RN]'s wishes and feelings are, or what he has in the past wished for"*, he has nonetheless plainly evaluated RN's likely compliance with the practicalities of vaccination, as well as identifying the inappropriateness of any use of force beyond keeping his arm still. In this investigation, the Judge has, in fact, harvested RN's likely 'feelings' to some degree. In circumstances where a protected party lacks capacity to understand the decision, resistance or cooperation in the process is, nonetheless, an important facet of their own decision making. It is manifestly different from a capacitious decision, but it is not without evidential value. Indeed, in questions of this kind, it is an important aspect of the forensic jigsaw. The Judge plainly took this into account in his endorsement of the care plan. The care plan makes the following observations:

> *"During the vaccination process, in order to make the experience as pleasant as possible, we would propose to place hands on RN for the purposes of keeping his arm still, to ensure that RN's injection site is correctly identified and enable an accurate delivery of this vaccination. We would further propose to place a hand on RN's lower arm or hand for the purposes of offering reassurance during this process. No physical restraint shall be used during the administration of this vaccination.*
>
> *If RN attends for his vaccine and at any point is clearly anxious/distressed, attempts will be made by staff and the administering clinician to reassure him and explain the process again. If these attempts succeed, and RN is comfortable with what is about to occur, the vaccine will be administered. If RN remains distressed and highly anxious, the process will be aborted.*
>
> *Following a failed attempt to administer a vaccination to RN, a further appointment would be booked within 28 days. For this second attempt to administer the vaccination, we would seek to adopt the same procedure as previously, but could also consider offering to administer the vaccination in the vehicle that RN arrives in. For clarity, no sedative or anxiolytic medication or any additional physical restraint would be used for any subsequent attempts."*

18. It also requires to be highlighted that in his summary and application of the case law, Judge Burrows made the following observation:

> *"I must also consider how the vaccination would have to be administered. In the case of a very resistant patient, in circumstances where there would have to be use of force to facilitate the administration of the vaccine it may be that the best*

> *interests balance would be tilted against vaccination even though it would reduce P's risk of harm due to the vaccine: see SS v Richmond upon Thames [2021] EWCOP 31, where Hayden, J. refused to authorise the administration of the vaccine."*

19. Mr Diamond's central ground of appeal, indeed the only one set out in his skeleton argument, is predicated on an elevated construct of parental rights. He described it in these terms:

> *"The Learned Judge erred in his judgment by an incorrect application of Article 8 ECHR; and in the application of Common Law Fundamental Rights in relation to parental rights as articulated by Gillick.*
>
> *It is important to recognise that RN lives at home cared for by a devoted mother TN. This is, par excellence, a family life issue with the role of State limited to assisting the family. Parental rights can only be overridden in extreme and limited circumstances of failing to care for the child."*

20. Mr Diamond contends that parental rights have both a common law and a statutory foundation. He characterises them per James LJ as *"one of the most sacred of rights"* (*Agar-Ellis v Lascelles (1878) 10 Ch.D 49 at [71])*. He contends that the primary responsibility for the upbringing of children rests with parents: *Gillick v West Norfolk and Wisbech Health Authority [1986] AC 112*. Mr Diamond highlights the following passage from the judgment of Lord Scarman:

> *"In the light of the foregoing, I would hold that as a matter of law the parental right to determine whether or not a minor child below the age of 16 will have medical treatment terminates when the child achieves a sufficient understanding and intelligence to enable him or her to fully understand what is proposed. It is a question of fact…."*

21. From all this, Mr Diamond advances the following proposition:

> *"The logic of this proposition of law is that if a child lacks capacity to understand, the parental right for the protection of the child continues.*
>
> *RN lacks capacity; and S''s parental rights continue in full, especially in the home setting. There is no 'magic' about an age: 16, 18 or, as in this case, 22 years. TN has parental responsibility for RN as he lacks Gillick competence."*

22. There is no logical nexus between the propositions that Mr Diamond has advanced and the submission he makes above. An adult who lacks capacity is not and should never be treated as a child. That paternalistic approach has long ago been consigned to history and recognised for what it is, a subversion of adult autonomy.

23. Mr Diamond contends that what he terms to be 'Common Law Fundamental Rights' (CLFR) are potentially more extensive than the Convention Rights, embodied in the European Convention on Human Rights. He articulates this in these terms:

> *"It is important to note that CLFRs may be broader than their equivalent Convention rights: first, the ECHR is a 'floor' and not a 'ceiling' of protection, and applies a minimum guarantee across a wide number of European states (part of the logic of the "margin of appreciation" is that states may opt for a higher level of protection for rights); second, the purpose of a constitutional right is not to provide outer limits for state action but to require sufficient parliamentary authorisation for limitations of rights which must still be Convention-compliant. In this case, the MCA lacks the authorisation."*

24. Mr Diamond concludes thus:

> *"The concept of a modern, liberal democratic State rejects the notion of a universal and state-imposed set of values but allows each individual (and, by implication, each family) to chose their own notion of the "good": the principle is live and let live. Liberalism's uniqueness is that individuals are free to choose their own "good"."*

25. I am bound to say that this elegantly expressed sentence strikes me as supporting the exact opposite of the case Mr Diamond is seeking to advance. It is RN's freedom that is to be protected here and not that of his mother. As is clear from this judgment, RN has a quality of life which is dignified and meaningful. I emphasise again, that he is capable of expressing both his enjoyment and his displeasure, his acquiescence and his resistance. The care plan reflects these fundamental facets of his autonomy and dignity.

26. The notes of the meeting between RN and his accredited legal representative reveal that both his mother and her friend, J, were present throughout the meeting and both articulated a strong, principled resistance to the vaccination plan. J particularly so. This does not strike me as facilitative of RN's rights as I have identified them. The views of parents, friends, and family members are invariably helpful when considering the wider non-medical aspects of a 'best interests' decision. But their relevance is to illuminate the broader canvas of P's circumstances, in which his best interests might be assessed. It is not to provide a platform for their own opposition to a plan which, objectively, is in P's best medical interests. In SD v Royal Borough of Kensington & Chelsea [2021] EWCOP 14, when the vaccine was still very new, I was required to consider arguments surrounding the vaccine's safety and efficacy. Judge Burrows made specific reference to that case, in these terms:

> *"In an important passage, which has become central to most of these cases, he stated:*
>
> *"...it is not the function of the Court of Protection to arbitrate medical controversy or to provide a forum for ventilating*

> *speculative theories. My task is to evaluate [P's] situation in light of authorised, peer reviewed research and public health guidelines and to set those in the context of the wider picture of [P's] best interests."*

27. Children are not chattels of parents. Our domestic law emphasises responsibilities rather than rights. In most situations, a parent will have ultimate responsibility for taking decisions concerning their children's health, education, and welfare. It is obviously right that this should be the case, but it is not ubiquitously true. Parents do not have absolute rights in respect of their children. Occasionally, for example, in the sphere of serious medical treatment, parents are sometimes ambushed by their own grief and distress which ill-equips them to identify where the best interests of their children lie. Thus, I reject Mr Diamond's primary proposition and, inevitably, therefore, the analogy he seeks to make with adults who lack capacity. In any event, however, incapacitious adults are entitled to the same choices and opportunities as the rest of the adult population. These rights are more extensive than those available to children. They include rights to forge personal and sexual relationships, to marry etc. The Mental Capacity Act 2005 imposes an obligation actively to promote P's decision taking however limited the sphere might be in which it can be exercised. It also requires assessment of wishes and feelings, even where P lacks the ability to understand, weigh or evaluate the decision in focus. Thus, the law extends the freedoms of adulthood to all adults, which includes the incapacitious. Any other approach would be discriminatory.

28. I have already said that there is strong evidence here that the greater risk emerges if RN is not vaccinated. Though he cannot absorb the issues for himself, he is perfectly able to decide whether to cooperate or reject the vaccination. This, for the reasons I have discussed above, is an important facet of RN's own autonomy on this issue, which however limited its ambit may be, nonetheless requires to be respected. The exercise of his autonomy may be circumscribed and confined by his learning difficulties, but it has not been extinguished. I consider that Mr Diamond's argument rather than advancing "modern liberal-democratic values" is regressive and fails to afford appropriate respect to people with disabilities who lack capacity in specific spheres of decision making. It is also discordant with the principles embodied in the Convention on the International Protection of Adults 2000.

29. Finally, it was argued that the 'particular complexities' of this case require the instruction of a further expert. This was not advanced before the Judge below nor is it set out in the skeleton argument, on behalf of TN, dated 5th December 2022. As I understand it, the expertise identified is virology. The identification of risk here has been focused on the tetralogy of Fallot in respect of which Dr A's expertise is entirely relevant, indeed, that is why he was instructed.

30. Mr Lewis, on behalf of RN, by his accredited legal representative, makes the following forthright observations:

> *"As a person with learning disabilities, [RN] was in "priority group 6" in the vaccine rollout and was entitled to receive his first vaccination in May 2021. The ALR regrets that his case has still not been determined, and [RN] has been denied protection*

> *against a potentially fatal disease. Luck has played a significant role in [RN] avoiding ill-health or death.*
>
> *The evidence by all health and care professionals involved in [RN]'s care was that he should receive the vaccinations. The reality is that [TN] is not appealing against a best interest's decision. Rather, she wants the court to reject (as she does) the science that has saved millions of lives worldwide. She wishes that the MCA did not exist, and that parents of disabled children could make decisions for them even in their adulthood. There is nothing that HHJ Burrows or indeed the appeal court could say that would change [TN]'s mind about how unproven and dangerous she considers the Covid-19 vaccinations to be.*
>
> *[TN]'s view was not supported by any medical evidence. She was given the opportunity over the course of several months in which she could have made an application to introduce her own expert evidence. She did not. This was a straightforward case where the evidence was not delicate or finely balanced. HHJ Burrows weighed up the evidence and correctly applied the law. The ALR invites the court to refuse [TN] permission to appeal."*

31. Whilst, with respect to Mr Lewis, I would not express myself in quite these terms, I agree that the evidence upon which the Judge was required to take the decision could not be described as delicate or finely balanced, nor is there any error in law. Accordingly, I dismiss the application for permission to appeal.

32. I do not doubt that the mother will be disappointed by this and whilst I consider the Judge was entirely right to rely on the established empirical conclusions underpinning the guidance, I respect the sincerity and strengths of her beliefs. There can be no doubt that she has, throughout his life, provided the best possible care for her son. His joyful personality and resilience is a great credit to him but it is his mother who has provided a quality of care for him in which these delightful and engaging aspects of his personality have been given the opportunity to blossom and grow. Though much of it goes beyond the scope of this appeal and was prepared before TN engaged counsel, I have given very great thought to everything that she has written, which I have no doubt is sincere. Ultimately, those views cannot be reconciled, either with the national medical guidance nor the specific evidence relating to the cardiology in RN's case.